



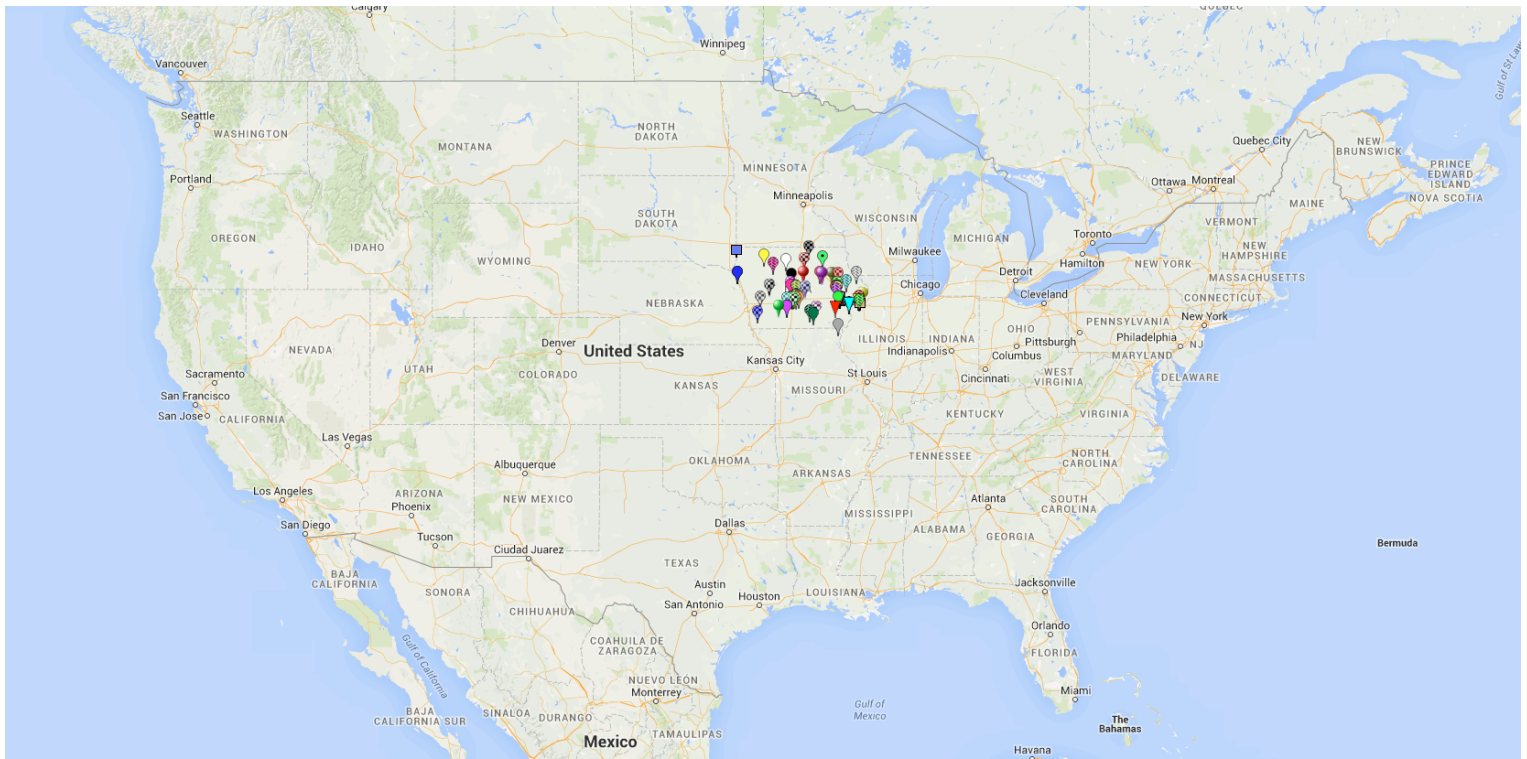
## **Chapter, Support group and Online Needs Assessment – 2015**

Background: From November, 2014 – March of 2015 the Brain Injury Alliance of Iowa conducted a statewide needs assessment with its membership, Chapters, Support Groups (Mason City, Tri-State/Dubuque, Quad Cities, Central/Ankeny, East Central/Cedar Rapids/Iowa City, Northwest/Spencer, Northeast/Waterloo) IBIRN sites (145) BISN peer support members, corporate members, past attendees of conferences, webinars and workshops, and more than 10,000 others stakeholders via secondary contacts from collaborators such as IDPH and others.

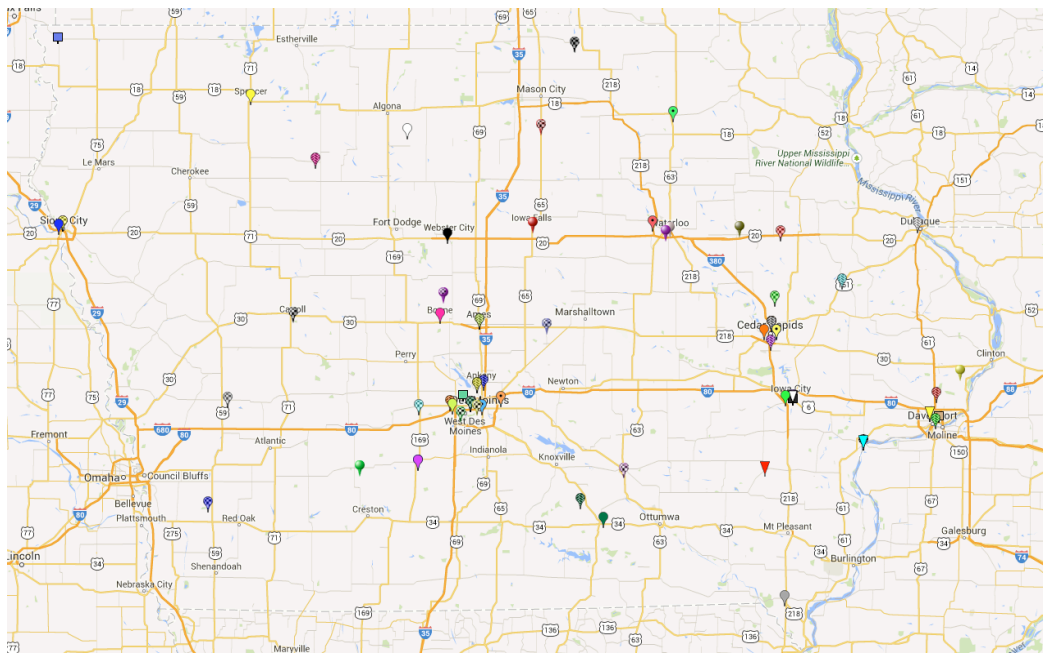
Copies of the web based survey and the Chapter/Support group questionnaires may be found in Appendix A.

We received 172 responses from both a web-based survey and via BIA-Iowa support groups. With the exception of the Southwest portion of the state these online responses were from across the state. See Charts 1 and 2 below:

**Chart 1 – Distribution of Zip codes from Web-based Respondents**

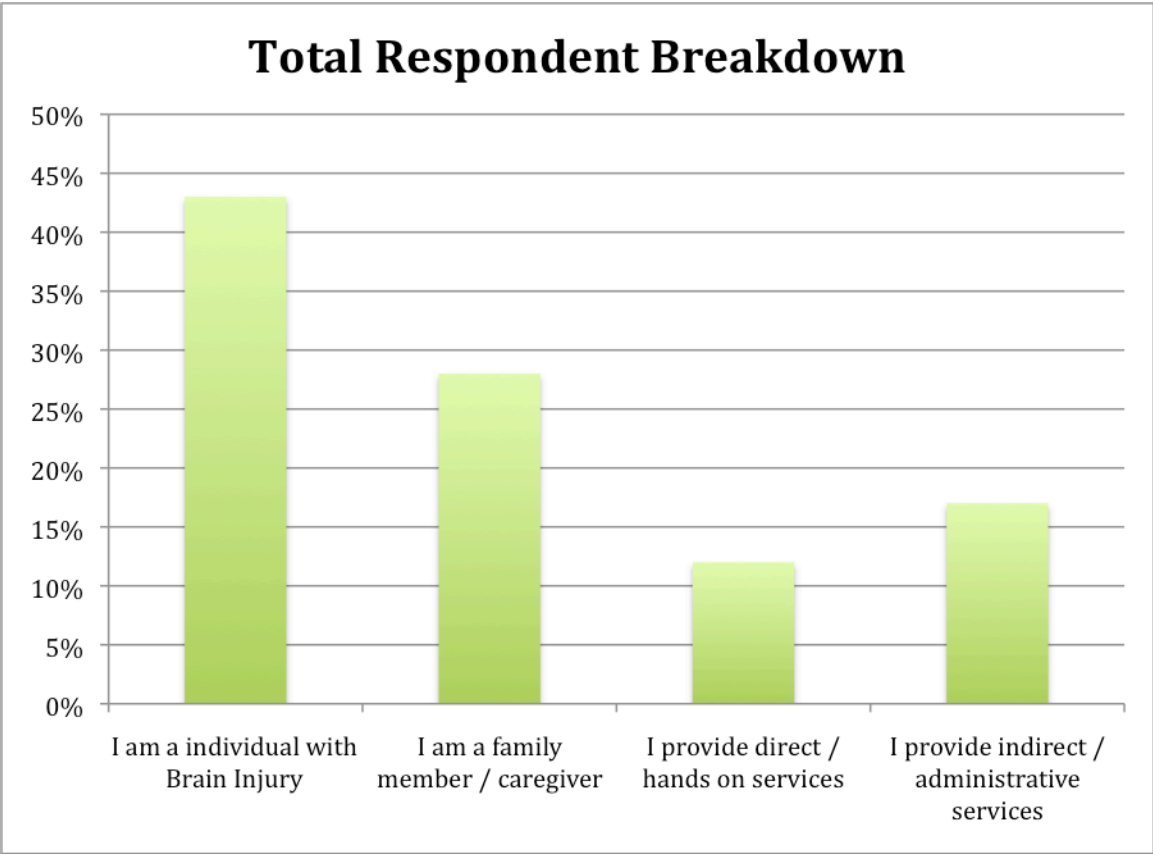


**Chart 2 – Distribution of Zip codes from Web-based Respondents (more localized view)**



Respondents to both the Online and Support Group based survey process were asked to identify themselves as primarily one of four groups. The web based survey gathered a distinct majority of “indirect / administrative service respondents” while the support groups manifested a much higher proportion of individuals with brain injury. See Chart 3 for total ratios.

**Chart 3 – Total Response Breakdown (Web based plus support groups)**



## **Summary:**

Below are the results from a qualitative analysis of the 2014 – 2015 Statewide BI needs assessment responses. This analysis combined the responses from the online and the support group data. Response items, areas and themes were first identified. Items, areas and themes were combined in cases where they aligned under a more major heading.

*The overall impressions from this 2014-2015 survey is that while many of the same challenges and concerns that have faced Iowans with brain injury and their families remain significant obstacles to them a change in questions this year compared to last year has elicited expected as well as new and interesting results. These include a strong sense that funding for services has stagnated in the area of private and public support as well as in the Iowa Medicaid program for Home and Community Based Services. A new and dominant theme was a identified need for increased awareness of the brain injury and its effect and impact on the individual and family. With regards to the provision of service providers responses indicated a need for improved understanding of brain injury and in dealing with individuals with brain injury in a respectful, individualized and person centered manner. The impact of brain injury along with subsequent changes and sequelae continue to arise as a need as in past years. In addition there is a dominant pessimism around recent improvement in the support systems in Iowa with some reference to better advocacy, specific service availability (community based neuro-behavioral programming) and better family support. A dominant theme around the worsening of the BI waiver waiting list and funding are also strong responses.*

***As a result of this survey consideration may well be given to the dominant themes around funding for services, awareness of brain injury among the lay public, increased training and/or education for service provider, and training/education for individuals, family and caregivers around the changes and impact of brain injury.***

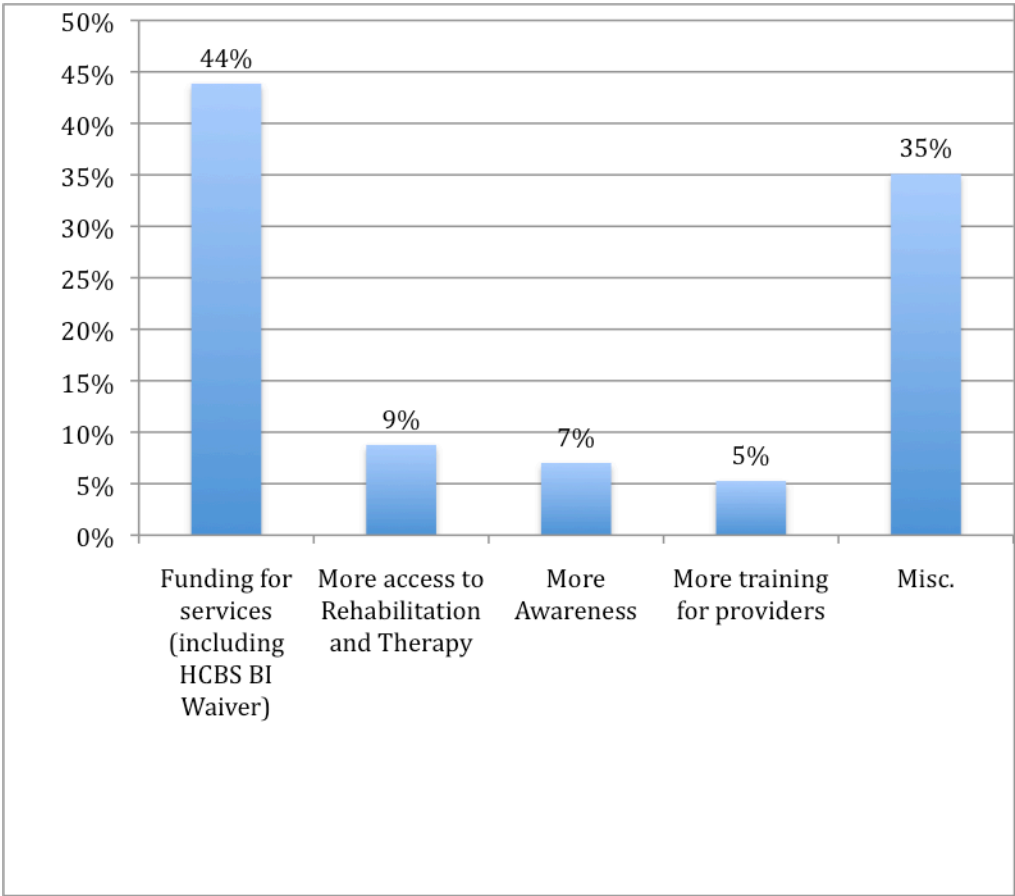
### **The Detail:**

Unlike prior years the response categories from the online survey AND the support groups aligned thematically in the dominant (top 4) areas.

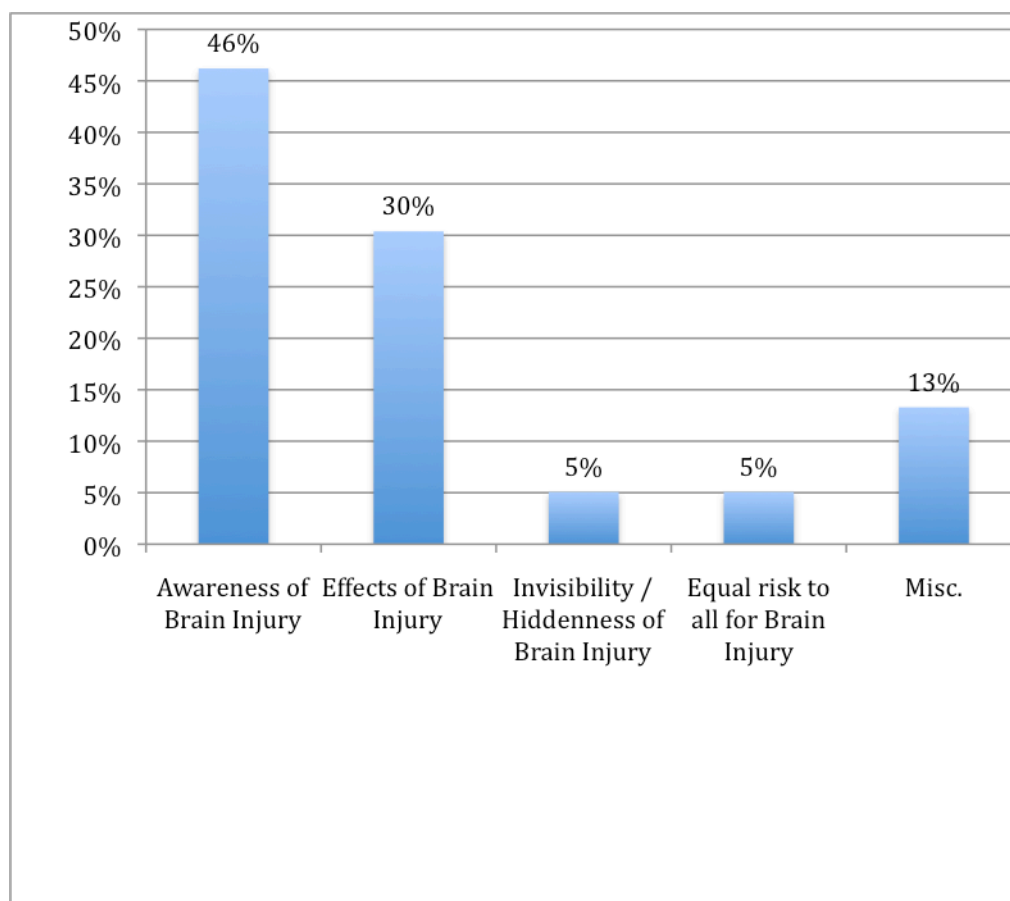
Below are charts with the percentage of response themes calculated based on the number of comparable comments (themes) compared to the total number of distinct qualitative comments. The “Misc.” category represents comments that were unique or themes with few comments.

3. What do think needs to be done to improve statewide services and supports for individuals with TBI and their families?

(114 total responses)

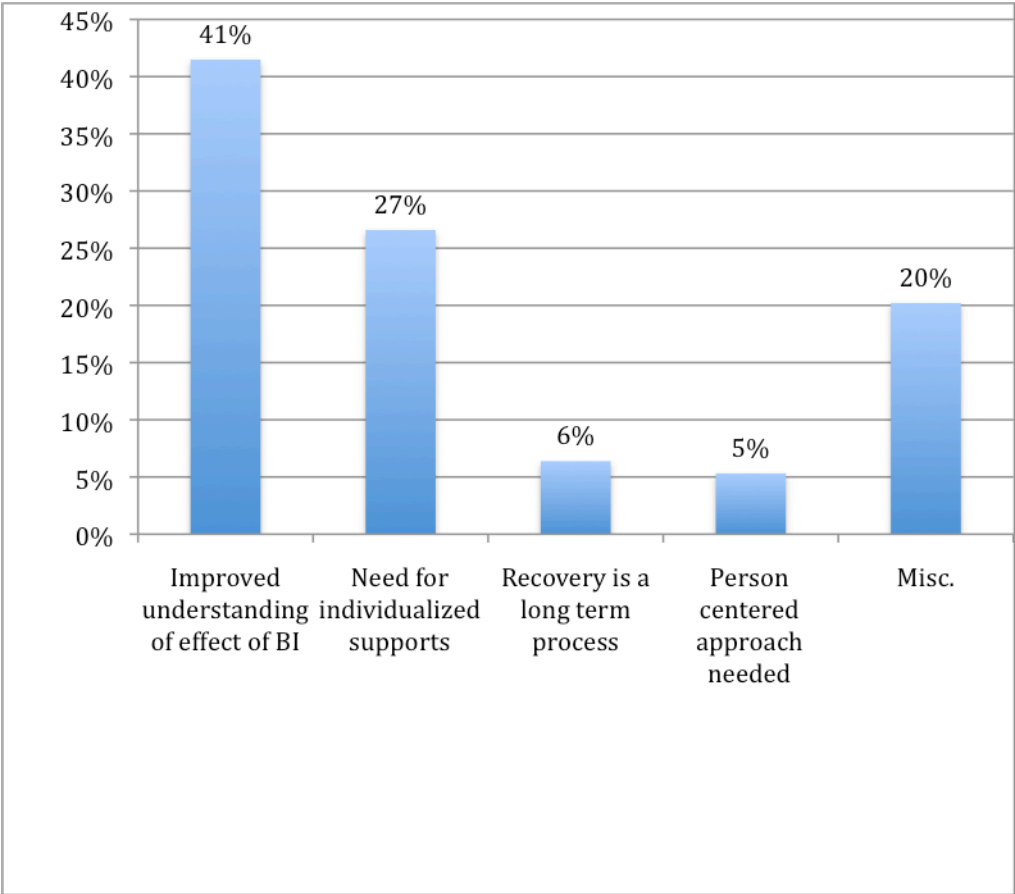


**2. What's one thing about brain injury you want lay people in your community to better understand?**  
(158 total responses)

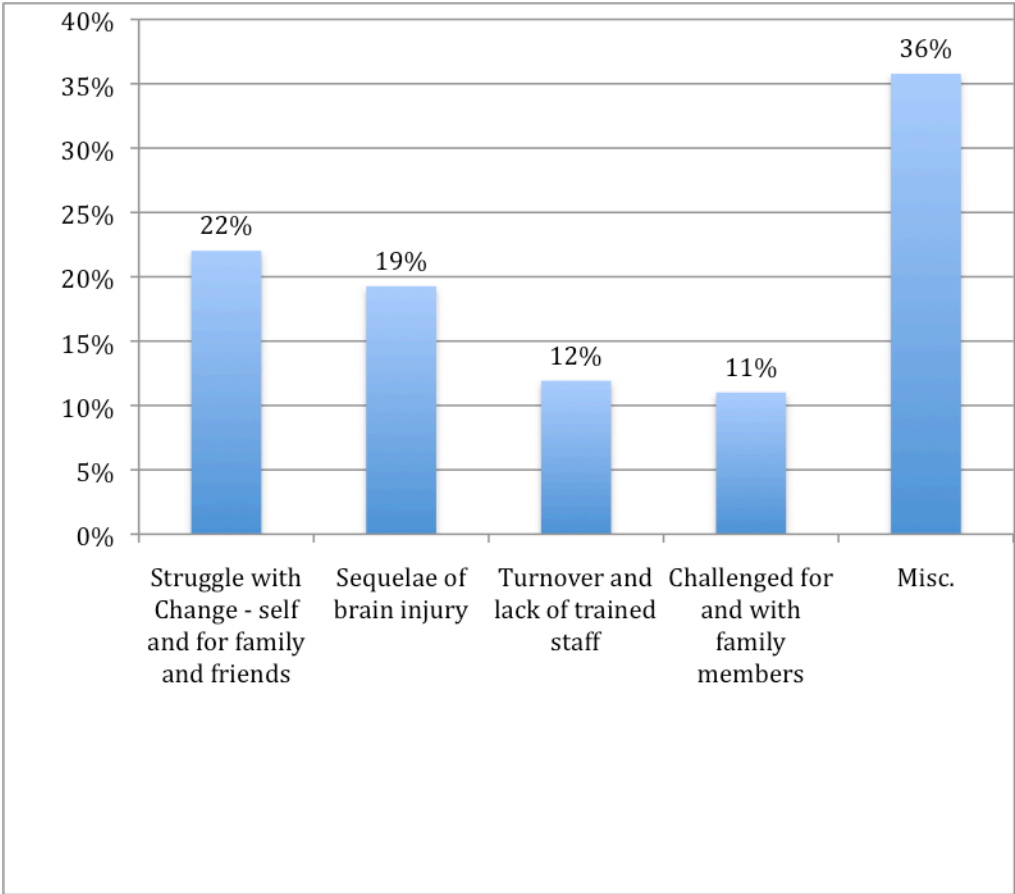


**3. What’s one thing about brain injury you want health care or disability services professionals to better understand?**

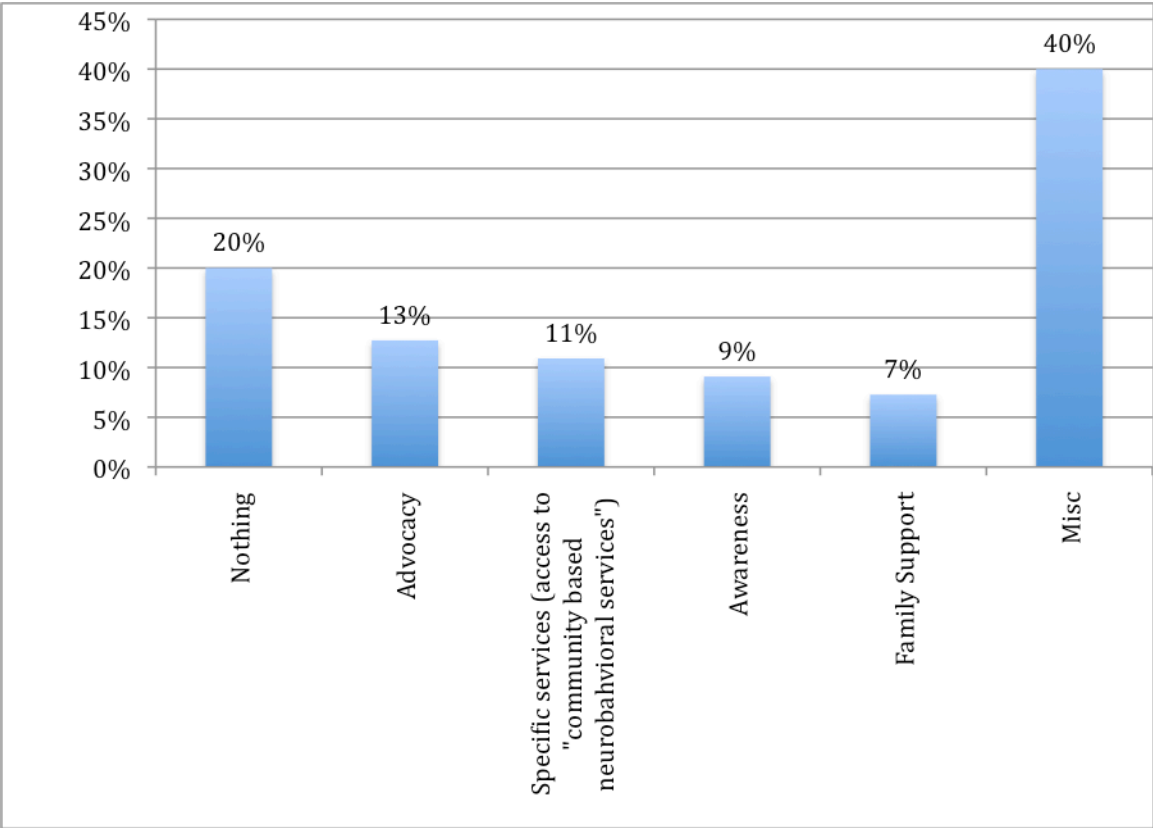
(94 total responses)



4. What is the hardest, or most challenging, thing about brain injury for you?  
(109 total responses)

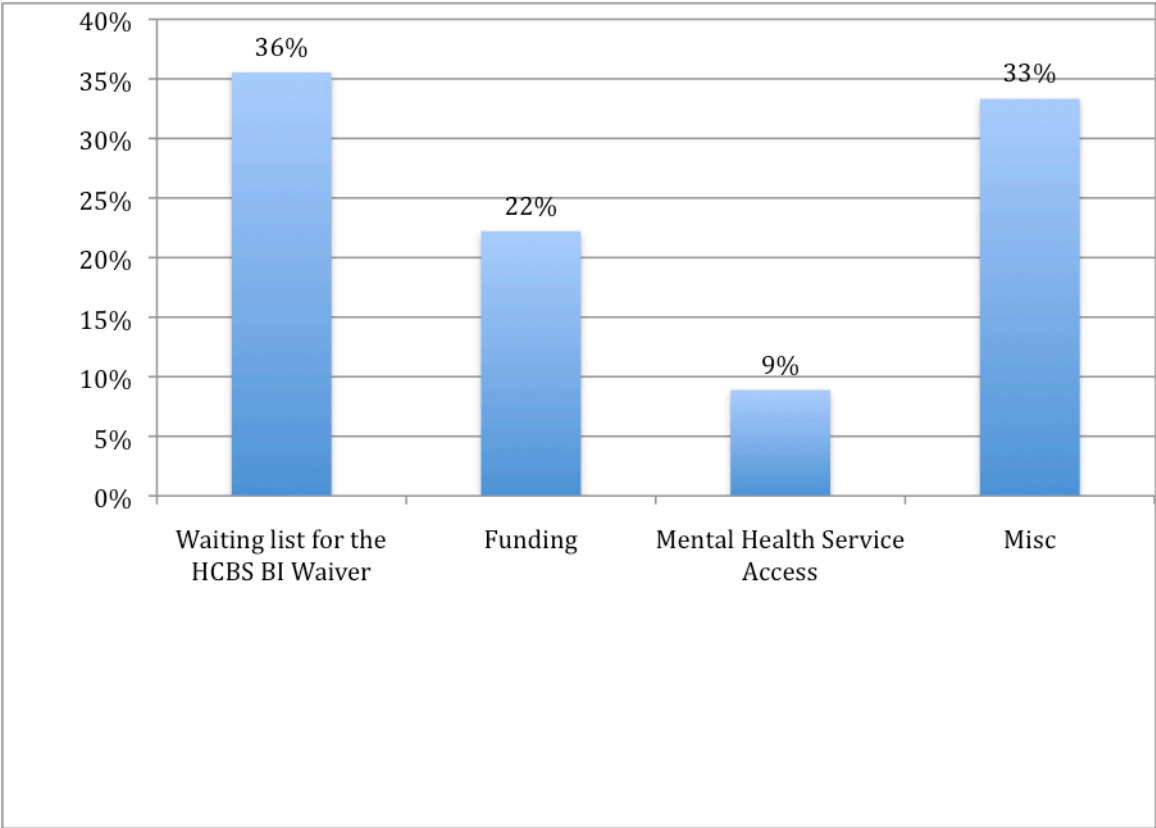


5. What, if anything, has improved in the service and support system in Iowa this past year?  
(55 comments)





6. What, if anything, has worsened in the service and support system in Iowa this past year?  
(45 comments)



7. Additional Comments?

Additional comments were varied with no major themes emerging. They tended to reinforce comments that had been made in prior questions.